

# Ryan White CARE Act Amendments of 2006

## Section-by-Section

### Section 1. Short Title.

This Act may be cited as the “Ryan White CARE Act Amendments of 2006.”

### Section 2. Reauthorizations.

The following CARE Act programs are reauthorized through fiscal year 2010:

- (1) Baby AIDS grants—Provides assistance to states to reduce perinatal HIV transmission and to care for pregnant women and children impacted by HIV.
- (2) Partner notification grants—Provides assistance to states to conduct partner notification services.
- (3) Title III— Early Intervention Services
- (4) Title IV—Women, Infants, Children and Youth and General Provisions
- (5) Titles I and II—Provide funds for eligible metropolitan areas and for states and territories
- (6) AIDS Education and Training Centers and Community Based Care

### Section 3. Definitions.

For purposes of this bill, the following terms are defined:

- ‘Partner Notification’
- ‘Primary Medical Care’
- ‘Routine Testing’

### Section 4. Funding for Primary Medical Care.

Requires that at least 75 percent of funding under of all Ryan White CARE Act programs be spent on primary medical care.

### Section 5. Supplemental Treatment Drug Grants Safety Net.

Requires that CARE Act funds left unspent for two years be redistributed through the AIDS Drug Assistance Program (ADAP) supplemental grant program.

Revises the current funding structure of the supplemental ADAP grants, authorizing an amount up to 8 percent of the amount appropriated for ADAP. If the amount appropriated plus the

amount redistributed from unobligated balances are less than 5 percent of the amount appropriated for ADAP, then sums necessary to ensure at least \$35 million shall be transferred into the supplemental from all other components of the CARE Act in proportion to the actual amount of the overall CARE Act they represent. Additionally, up to \$5 million from administrative expenses within the Health and Resources and Services Administration may also be directed into the supplemental.

#### Section 6. Ensuring Equitable Per Case Funding.

Provides for more equitable funding regardless of geography or stage of infection by:

- (1) Re-iterating present law requiring reported cases of HIV, as confirmed as reliable and accurate by the Director of the Centers for Disease Control and Prevention, become the basis of funding formulas for all CARE Act programs beginning in fiscal year 2007.
- (2) Ensuring states with newer surveillance systems are protected from losing funding by allowing those states that established HIV reporting between October 2000 and October 2006 to use HIV prevalence estimates determined by the CDC until fiscal year 2009 when all states and metropolitan areas will rely on reported and confirmed cases of HIV/AIDS for funding.
- (3) Phasing out the “double counting” that results in patients being counted twice—once for Title I funding and again for Title II funding.
- (4) Rescinding “supplemental grants for emerging communities” that benefit select areas, thereby giving states the discretion to better target funding to emerging or underserved areas.

#### Section 7. Ensuring Funding Corresponds with Epidemiological Trends.

Ensures that federal support follows the direction of the epidemic by:

- (1) Allowing up to 60 metropolitan areas with a population of at least 500,000 with 2,500 living HIV cases to qualify for Title I funding.
- (2) Re-establishing EMA boundaries under the Office of Management and Budget definition of a metropolitan statistical area.
- (3) Removing the “grandfathering” provision that continues funding to metropolitan areas eligible in fiscal year 1995 and earlier that no longer meet eligibility criteria for Title I funding if such areas do not re-qualify for eligibility within the next two consecutive fiscal years.
- (4) Phasing out the Title I “hold harmless” provisions by fiscal year 2009.

#### Section 8. Prohibition on Funding for Entities that Prohibit or Impose Barriers on Partner Notification.

Prohibits CARE Act funding to any jurisdiction that prohibits or imposes barriers to partner notification services.

#### Section 9. Coverage for Treatment for Hepatitis B and Hepatitis C Co-infection.

Ensures that those patients with HIV co-infected with hepatitis B and C receive proper care by:

- (1) Authorizing CARE Act programs to provide treatment for co-infected patients.
- (2) Allowing special projects of national significance to address issues related to the care and treatment of co-infected patients.
- (3) Allows AIDS Education and Training Centers to educate health care and service providers on identification, treatment and prevention for co-infected patients.

#### Section 10. Planning Councils.

Updates the roles and enhances accountability of planning councils by:

- (1) Adding representatives from faith-based organizations and individuals who are co-infected with HIV and Hepatitis C or Hepatitis B to councils.
- (2) Requiring conflict of interests of planning council members to be reported and available to the public.
- (3) Requiring a majority of the council to have no financial conflicts of interests with recipients of funding that is allocated by the council.
- (4) Requiring the chief executive of an EMA to approve planning council decisions.

#### Section 11. Reduction of Administrative Costs.

Reduces overhead costs by including expenses associated with EMA planning councils and planning for the allocation for the expenditure of Title I funds as a component of administrative costs.

#### Section 12. Rapid Routine Testing.

Improves efforts to identify those who are infected by:

- (1) Providing routine rapid HIV testing for all clients at all facilities receiving funding from the Department of Health and Human Services.
- (2) Requiring routine testing of pregnant women and newborns whose mothers' HIV status is unknown being cared for at a federally funded facility or covered under a federal health program.
- (3) Requiring timely and appropriate counseling and treatment referrals for all those who test positive for HIV antibodies.

- (4) Requiring that CDC purchase and distribute no fewer than 1.5 million rapid HIV tests annually.

#### Section 13. ADAP Recommended Formulary and Report Card.

Improves efforts to ensure optimal and up to date treatment for patients and to understand and address treatment limitations by requiring HHS to develop a minimum standard formulary for AIDS treatment and report annually to Congress on state ADAP waiting lists and formulary restrictions and the actions being taken to address such treatment restrictions.

#### Section 14. State Flexibility In Providing HIV/AIDS Care.

Provides states flexibility in providing HIV/AIDS care by allowing states to choose to provide CARE Act treatment as part of Medicaid as long as such funds are not used to supplant existing funding for such care already is provided under Medicaid.

#### Section 15. Prices Paid for Therapeutics for ADAP.

Seeks to ensure that all Ryan White CARE Act programs are receiving optimal prices for medications by:

- (1) Requiring routine analysis and reporting of the prices paid for therapeutics by the Health Resources and Services Administration to Congress.
- (2) Requiring all entities providing treatment to CARE Act patients to coordinate the purchase of therapeutics with ADAP.

#### Section 16. Authorization of Appropriations for ADAP.

Authorizes an increase of \$70 million of new funding for ADAP per fiscal year through 2010.

#### Section 17. Special Projects of National Significance.

Provides up to \$15 million annually for special projects of national significance which shall include the following:

- (1) Pilot programs to evaluate various forms of partner notification.
- (2) Development of a standard electronic client data system to improve coordination of coverage provided to patients under the CARE Act and other federal health programs.
- (3) Study and provide recommendations for best practices for disease management for patients living with HIV/AIDS.

### Section 18. Housing Opportunities for Persons with HIV/AIDS.

Improves efforts to provide federal housing assistance to those with HIV/AIDS by:

- (1) Updating formulas for the Housing Opportunities for Persons with HIV/AIDS (HOPWA) to make such funding based upon living cases of HIV/AIDS, rather than cumulative cases of AIDS, by fiscal year 2009. A phase in will protect jurisdictions from any dramatic changes in funding that might occur.
- (2) Requiring that at least 75 percent of HOPWA funds are utilized for the construction, maintenance or development of housing assistance for those with HIV/AIDS.

### Section 19. Ensuring Stability in Infrastructure.

Ensures that with the numerous changes made under this act, the care infrastructure provided under Title II base grants does not experience dramatic reductions from year to year. States would not experience more than a 5 percent loss each year (based on fiscal year 2005 funding levels).

### Section 20. Coordination of Grantees.

Increases coordination between the states, cities, and other care providers by providing state AIDS officials with the authority to request and obtain all information necessary for states to coordinate HIV care and treatment with other federally funded projects to maximize efficiency and effectiveness of HIV/AIDS services.

### Section 22. Technical Corrections.

## How the Ryan White CARE Act Amendments of 2006 Improves Our Federal Response to HIV/AIDS?

The Ryan White CARE Act Amendments of 2006 reauthorizes the nation's largest HIV/AIDS-specific care and treatment program for an additional five years. The CARE Act was first authorized in 1990 and funding has grown from \$257 million in 1991 to over \$2 billion in 2006. The program and its grantees serve 533,000 people each year.

While funding for the CARE Act has increased dramatically, thousands of Americans with HIV are on waiting lists for access to life saving AIDS medications and many others face formulary restrictions. In fact, about half of those infected with HIV in the U.S. are not receiving medical care. One in four with HIV/AIDS, don't even know they are infected.

This bill makes a number of important reforms to address these shortcomings:

- (1) Provides more equitable distribution of federal funding to ensure that all Americans living with HIV are recognized and valued equally for the purpose of federal funding and care services.
- (2) Targets more resources to areas with waiting lists for and restrictions on treatment.
- (3) Prioritizes primary medical care, including doctors visits, tests and medications.
- (4) Authorizes an increase of \$70 million annually for the AIDS Drug Assistance Program (ADAP), which provides life saving medication to underinsured Americans living with HIV.
- (5) Guarantees at least \$35 million annually for ADAP supplemental grants targeted to needy areas.
- (6) Redirects unspent CARE Act funding into ADAP supplemental grants.
- (7) Reduces administrative, planning and other non-essential costs.
- (8) Improves efforts to identify those with HIV and get them into treatment early when medication can be the most effective.
- (9) Provides greater flexibility, coordination and accountability of CARE Act funds.
- (10) Allows treatment coverage for HIV-positive individuals co-infected with Hepatitis B and/or Hepatitis C and seeks to increase health care providers' knowledge of co-infection treatment.

## Ryan White CARE Act Amendments of 2006 Bill Summary

It has been 25 years since the first cases of what is now known as HIV/AIDS were recognized. Since that time, at least 1.6 million people in the U.S. are estimated to have been infected with HIV, including more than 500,000 who have already died. The Centers for Disease Control and Prevention (CDC) estimates that 40,000 American become newly infected with HIV each year and more than one million are now living with HIV/AIDS.

One in four of those infected do not know it and are, as a result, being denied life saving treatment and may be unknowingly infecting others. Furthermore, approximately half of those infected are not receiving medical care. Racial and ethnic minorities have been disproportionately affected by HIV/AIDS since the beginning of the epidemic, and now represent the majority of new AIDS cases and African American women represent the fastest growing proportion of new cases.

It is an indictment of our failed policies that the federal government spends nearly \$20 billion annually on HIV/AIDS-related programs and so many are going undiagnosed and untreated and the disease continues to spread unabated.

This is a direct result of ineffective policies, misplaced priorities, and a lack of accountability.

The Ryan White CARE Act Amendment of 2006 seeks to address these shortcomings. It first prioritizes early identification and access to primary medical care and treatment. It provides more equitable funding that better targets federal resources to underserved populations and emerging areas being impacted by this epidemic. It also ensures greater accountability for how funds are spent.

### Prioritizing Early Diagnosis and Treatment

The Ryan White CARE Act Amendments of 2006 emphasizes early intervention by providing greater opportunities for diagnosis and guaranteeing access to medical care.

To identify those with HIV who are unaware of their status, this bill would expand access to testing and remove barriers that prevent diagnosis. At least 1.5 million rapid tests would be made available annually. HIV testing would become a routine medical procedure, as recommended by CDC, in facilities receiving federal funding and for patients covered by federal health programs, specifically pregnant women and newborns. Furthermore, states would be encouraged to remove barriers that prevent alerting those who may have been exposed to HIV that they should seek testing and, if infected, care. All those identified with HIV would receive appropriate counseling and linked to care.

To ensure optimal treatment for all those identified with HIV, this bill would provide additional resources for treatment and seek to update and improve care services. At least 75 percent of all

CARE Act funds would be required to be spent on primary medical care, including doctor visits and prescription drugs. Each year, an increase of \$70 million would be authorized for the AIDS Drug Assistance Program (ADAP) and an additional amount of at least \$35 million would be guaranteed annually to provide assistance to patients living in states with ADAP shortfalls. Appropriate care for patients living with HIV who are also co-infected with hepatitis B or C would now be provided by the CARE Act and states would have the option to use CARE Act funds to supplement AIDS-related treatment provided under Medicaid. A standard formulary for AIDS drug treatment would be developed by the Department of Health and Human Services (HHS), which would report annually on the progress of providing such care. In addition, best practices for disease management for patients with HIV/AIDS and an electronic patient information system would be developed to ensure patients are receiving appropriate and coordinated care.

#### Ensuring Resources Are Targeted Equitably and to Those Most in Need

The Ryan White CARE Act Amendments of 2006 emphasizes targeting resources equitably and to those most in need.

To more equitably distribute federal resources, the bill ensures that all those living with HIV/AIDS are recognized in funding formulas beginning in fiscal year 2007. Formulas would also be updated to ensure HIV/AIDS cases are not counted more than once and that deceased patients are no longer used to determine funding for both the CARE Act and HOPWA. To ensure stability, these changes would be phased in and states with newer HIV reporting systems will be permitted to use estimates of HIV/AIDS prevalence.

To better target funding, additional funding will be provided under the ADAP supplemental that provides funding for AIDS medication for patients in areas with severe need.

#### Ensuring Accountability of CARE Act Funds

The Ryan White CARE Act Amendments of 2006 emphasizes accountability at all levels to ensure that federal resources are spent wisely.

The Health Resources and Service Administration (HRSA) must routinely analyze and report the costs for AIDS drugs to ensure that the CARE Act is receiving the best possible prices. Annual “report cards” would be issued evaluating states’ efforts to provide patients with the most up to date AIDS treatment and identifying the barriers to doing so. A majority of Title I planning council members must be free of any conflicts of interest and any such conflicts of council members must be publicly disclosed. The local chief executive officer must approve of CARE Act funding decisions and states would have more authority to coordinate care. Overhead, administrative costs and other non-essential expenditures would be reduced to ensure more funding for primary medical care and treatment under the CARE Act and housing assistance under HOPWA.



## Ryan White CARE Act Amendments of 2006: Reflecting the White House Principles

President Bush has repeatedly urged the Congress to reauthorize the Ryan White CARE Act, most recently in his 2006 State of the Union Address. Last year the Administration released a set of principles to guide the reauthorization. Nearly all of the President's principles are included in the Ryan White CARE Act Amendment of 2006.

### President's Principle: Focus on Life-Saving and Life-Extending Services

<b>President's Proposal</b>	<b>Bill Provisions</b>
Establish a set of core medical services	Section 13 provides a recommended standard formulary for AIDS treatment; Section 17 develops best medical practices for disease management for HIV/AIDS patients.
Require 75 percent of CARE Act funds be used for core medical services	Section 4 requires at least 75 percent of CARE Act funds be spent on primary medical care and medications.
Maintain a list of ADAP core medications	Section 13 requires the development of a recommended formulary of essential AIDS medications

### President's Principle: Increase Prevention Efforts

<b>President's Proposal</b>	<b>Bill Provision</b>
Require routine HIV testing	Section 12 requires routine HIV testing in all federally funded facilities and for patients covered under federal health programs and provides at least 1.5 million rapid tests annually for testing efforts
Encourage states to conduct partner notification	Section 2 reauthorizes federal funds to assist states with partner notification efforts; Section 8 prohibits barriers to conducting partner notification

### Increase Accountability

<b>President's Proposal</b>	<b>Bill Provision</b>
Maintain requirement for formulas to be based upon HIV case data beginning in Fiscal year 2007	Section 6 maintains current law requiring CARE Act formulas to incorporate HIV case data in fiscal year 2007

Require coordination between state and local care delivery	Section 20 requires coordination between state and local care delivery
Eliminate double counting of HIV/AIDS cases between EMAs and states	Section 6 phases out provisions that result in cases being counted more than once
Eliminate Title I “hold harmless”	Section 7 phases out the Title I hold harmless by fiscal year 2009

### Increase Flexibility

<b>President’s Proposal</b>	<b>Bill Provision</b>
Redistribute unspent CARE Act funds to state ADAP programs with the greatest need	Section 5 redistributes unspent CARE Act funds the ADAP supplemental which targets states with severe needs
Title I Planning Councils are advisory and structured to the discretion of the mayor and member could not have conflicts of interest	Section 10 would require that the local chief executive officer to approve Planning Council recommendations, the majority of Planning Council members have no conflicts of interest, and conflicts of interests of planning council members be reported and disclosed.

## How Formulas Would Change Under the Ryan White CARE Act Amendments of 2006

The Ryan White CARE Act Amendments of 2006 revises funding formulas to more equitably distribute federal funds for both the CARE Act and the Housing Opportunity for Persons With AIDS (HOPWA) programs. The following is a brief description of how formulas would be updated:

### **Ryan White CARE Act**

#### ***Title I***

Living cases of HIV and AIDS would be the basis of funding formulas beginning in fiscal year 2007 as required under current law. Eligible metropolitan areas (EMAs) in states with newer HIV reporting systems, established between October 2000 and October 2006, CDC would provide estimates of living HIV cases in those areas for fiscal years 2007 and 2008. EMAs in states that do not have HIV reporting systems that have been verified by CDC as being reliable and accurate by October 2006 could only use living AIDS cases for determining Title I eligibility and funding, but could add HIV cases in the future if they enact a reporting system that meets CDC criteria for accuracy.

Because HIV data would be added to AIDS cases in determining Title I funds, eligibility for EMAs would be revised. Currently, an EMA must have reported at least 2,000 AIDS cases during the previous 5 years and have a population of at least 500,000. This bill would require an area of at least 500,000 to have at least 2,500 reported living cases of HIV. EMA boundaries would also be redesignated to meet more recent Office of Management and Budget definition of metropolitan statistical area.

Both the hold-harmless and grandfathering provisions enacted in 1996 would be phased out by fiscal year 2009. An EMA being held harmless would be guaranteed 50 percent of the funding it received in fiscal year 2006 in 2007 and 25 percent of that amount in 2008 and in fiscal year 2009, the EMA would receive the amount due under the regular formula. An EMA that has been grandfathered in 1996 or any other EMA that no longer meets eligibility for Title I funds would continue to receive funds unless it fails to meet eligibility for two consecutive fiscal years when it would no longer receive Title I funds.

#### ***Title II***

Living cases of HIV and AIDS would be the basis of funding formulas beginning in fiscal year 2007 as required under current law. States and territories with newer HIV reporting systems, established between October 2000 and October 2006, CDC would provide estimates of living HIV cases in those areas for fiscal years 2007 and 2008. States that do not have HIV reporting systems that have been verified by CDC as being reliable and accurate by October 2006 could only use living AIDS cases for determining

funding, but could add HIV cases in the future if they enact a reporting system that meets CDC criteria for accuracy.

The number of HIV/AIDS cases in EMAs in states that receive Title I funding would be subtracted from the number of HIV/AIDS cases used to determine Title II funding. Also, the Emergency Communities grants would be discontinued. These provisions would ensure that no case of HIV/AIDS is counted more than once for funding purposes.

The hold harmless provision would be revised to protect against dramatic shifts in funding while ensuring funding is targeted to areas based upon needs as determined by case loads. In fiscal year 2006, no state would experience a reduction in funding greater than five percent of the amount it received in 2005. This amount would increase by five percent annually and by 2010, every state would be guaranteed to receive at least 75 percent of the amount it received in 2005 regardless of the impact made by the changes in this bill.

### ***ADAP Supplemental***

Currently, three percent of the amount appropriated for ADAP is reserved for supplemental grants to States and territories with demonstrated severe need that prevents them from providing medications. The supplemental ADAP amount will be about \$23 million in fiscal year 2006.

This bill would fund the supplemental grants by:

- (1) Requiring that CARE Act funds from all Titles left unspent for two years be redistributed through the supplemental; and
- (2) A new separate authorization of up to 8 percent of the total ADAP appropriations. If ADAP was fully funded, this amount would rise from \$69.6 million in fiscal year 2007 to \$86.4 million in fiscal year 2010.

If the combined amount appropriated plus the amount redistributed from unobligated balances is less than 5 percent of the amount appropriated for ADAP, then sums necessary to ensure at least \$35 million shall be transferred into the supplemental from all other components of the CARE Act in proportion to the actual amount of the overall CARE Act budget they represent. Additionally, up to \$5 million from administrative expenses within the Health and Resources and Services Administration may also be directed into the supplemental.

### **Housing Opportunities for Persons with AIDS (HOPWA)**

HOPWA funds are currently distributed based upon cumulative AIDS cases. This means that those with HIV who have not progressed to AIDS are not included in funding formulas while patients with AIDS who are deceased are included.

The bill phases out funding based on deceased AIDS cases and phases in reported living HIV cases by fiscal year 2009.

In fiscal year 2007, 75 percent of HOPWA funding would be based on the existing formula that uses cumulative AIDS counts and 25 percent of the formula would be based on living HIV and AIDS cases.

In fiscal year 2008, 25 percent of the formula would be based on cumulative AIDS cases and 75 percent would be based upon living HIV/AIDS cases.

In fiscal year 2009, the HOPWA funding formula would be based upon only living cases of HIV and AIDS.

For those jurisdictions with newer HIV reporting systems, established between October 2000 and October 2006, CDC would provide estimates of living HIV cases in those areas for fiscal years 2007 and 2008. States that do not have HIV reporting systems that have been verified by CDC as being reliable and accurate by October 2006 could only use living AIDS cases for determining HOPWA funding, but could add HIV cases in the future if they enact a reporting system that meets CDC criteria for accuracy.